

12-31-2021


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[10.1097/jnc.000000000000238](https://doi.org/10.1097/jnc.000000000000238)

This is a non-final version of an article published in final form in Zgambo, M., Arabiat, D., & Ireson, D. (2021). It cannot happen, never: A qualitative study exploring youth views on disclosure of HIV diagnosis to their sexual partners in Southern Malawi. *Journal of the Association of Nurses in AIDS Care*, 32(6), 652-661. <https://doi.org/10.1097/JNC.000000000000238>

Zgambo, M., Arabiat, D., & Ireson, D. (2021). It cannot happen, never: A qualitative study exploring youth views on disclosure of HIV diagnosis to their sexual partners in Southern Malawi. *The Journal of the Association of Nurses in AIDS Care*, 32(6), 652-661. <https://doi.org/10.1097/JNC.000000000000238>

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<https://ro.ecu.edu.au/ecuworkspost2013/10524>

# ***It Cannot Happen, Never: A Qualitative Study Exploring Youth Views on Disclosure of HIV Status to Their Sexual Partners in Southern Malawi***

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## **Abstract**

With the availability of antiretroviral therapy, more children living with HIV live longer than before and grow into young adulthood. This study examined the concerns of youth about disclosure of an HIV diagnosis to their sexual partners and attempted to gain an understanding of their HIV status disclosure experiences, views, and plans. A focused ethnography was undertaken. Using semi-structured interviews, data were collected from 20 youth between the ages of 15 and 24 years who were attending an HIV clinic. The findings highlight that youth generally struggled to disclose their HIV status to their sexual partners. The most frequent reasons for concealing their HIV status was fear of relationship

termination, being unmarried, and fear that their sexual partners may reveal their HIV diagnosis to the community, thereby predisposing them to stigmatization, discrimination, and prejudice. There is a need to develop and strengthen HIV disclosure support groups for youth to help them develop life skills for overcoming HIV-related stigma.

**Key words:** discrimination, focused ethnography, HIV transmission, HIV status disclosure, living with HIV, Malawi, sexual behavior, sexual partners, stigma, youth

## **Background**

Two to three decades ago, many children living with HIV, frequently acquired through vertical transmission, were dying before their fifth birthday (Davies et al., 2016). However, with the availability of highly active antiretroviral therapy (ART), more children living with HIV are living longer and maturing into young adulthood (Davies et al., 2016). Globally, it is estimated that 37.9 million adults and children are living with HIV, of which about one million are in Malawi (UNAIDS, 2019). In Malawi, the prevalence of HIV among youth between the ages of 15 and 24 years is increasing each year, with over 30% of all new infections occurring in this population (UNAIDS, 2018). For most youth living with HIV, the transmission route is vertical (Davies et al., 2016).

The disclosure of HIV status to potential sexual partners is one of the essential public health strategies for ongoing prevention and control of HIV transmission (O'Connell et al., 2015). More youth should, therefore, know their HIV diagnosis and be able to disclose their HIV status to sexual partners for the adoption of safer sexual behaviors (Hampana & Rael, 2018; Weintraub et al., 2017). The disclosure of HIV status to sexual partners also increases the opportunities for receiving social support, enhancing self-management of HIV, and may motivate partners to engage in voluntary HIV counseling and testing (Yaya et al., 2015). Although evidence has shown that HIV disclosure benefits both youth and their communities, disclosure is often an individual act that may or may not occur, based on the influences of the prevailing societal and cultural dynamics (Mengwai et al., 2020). Earlier studies indicate that the advantages of HIV disclosure to sexual partners by youth are outweighed by the fear of unwanted community disclosure (Mengwai et al., 2020), fear of stigma and discrimination (Mengwai et al., 2020), negative self-image (Evangeli & Wroe, 2017), fear of violence, and rejection by peers (Colombini et al., 2016), as well as fear of personal embarrassment (Evangeli & Wroe, 2017). In addition, the negative cultural and religious perception of sexual

activity as a potential mode of HIV transmission is associated with immorality, and this is reported as a barrier to HIV disclosure (Nhamo-Murire et al., 2014). As a result, some youth who are aware of their HIV diagnosis self-isolate for fear of abandonment or rejection and being judged by the community for socially “inappropriate” sexual behaviors (Evangelini & Wroe, 2017).

Although disclosure of HIV status to sexual partners is a complex phenomenon, a significant proportion of youth living with HIV are engaging in risk-laden sexual behaviors, including having multiple sexual partners and unprotected sexual activity (Elkington et al., 2014; Mengwai et al., 2020). Malawi is one of several developing countries with reports of early sexual debut (below 15 years of age) and high engagement in risky sexual behaviors in youth, including by those living with HIV (Malawi National AIDS Commission, 2015; Pindani et al., 2014). Studies in this country have examined HIV status disclosure among people living with HIV in Malawi; however, these studies focused on patterns of HIV status disclosure to children of their HIV diagnosis by caregivers or health workers and between adult sexual partners (Hino et al., 2018; Kalembo et al., 2018; Mandalazi et al., 2014). No published study has yet investigated HIV status disclosure by youth living with HIV to sexual partners, despite current evidence of high engagement in risky sexual behaviors in this group.

There are unique needs and challenges associated with youth and their developmental stage. For example, it is essential to understand the dynamics of HIV status disclosure among youth while also considering the importance of peer pressure and developing a social identity (WHO, 2019a). The aim of this study was to examine the concerns, as well as experiences, associated with disclosure of HIV status to sexual partners among youth living with HIV in Malawi.

## **Methods**

### **Design**

This focused ethnographic study is part of a larger study designed to investigate the sociocultural context of HIV risk and sexual behaviors among youth living with HIV in Malawi. Focused ethnography and, more particularly, an interpretive approach, aims to better understand the subjective experiences of the participants through the integration of their personal and internal world experiences (Whitehead et al., 2018). Focused ethnography is a branch of traditional ethnography that adopts reformed approaches to data collection and engagement in the field (Wall, 2015). Unlike traditional ethnographies, the researcher can spend less time in the field while rigorously eliciting purposeful data using one or more data collection methods such as observations, recorded artefact, and in-depth interviews (Cruz & Higginbottom, 2013). This approach helps to define people's cultural understanding of a problem through the description of their thoughts, behaviors, and interactions within a cultural group (Wall, 2015). A cultural group is defined as any cluster of individuals sharing common experiences and characteristics, irrespective of their geographical boundaries (Cruz & Higginbottom, 2013). In this study, the distinct cultural group was youth living with HIV in Malawi.

### **Setting and Participants**

Twenty youth living with HIV were recruited to the study from a specialized outpatient clinic for people living with HIV, at Mwanza District Hospital in the Southern region of Malawi. Youth from this setting were eligible to participate if they were (a) between the ages of 15 and 24, (b) diagnosed with HIV (as verified by the recruiting nurse), (c) aware of their HIV status for at least 6 months, and (d) receiving care at the HIV clinic at Mwanza District Hospital. To diversify the sample and to ensure the representativeness of

youth living with HIV in the Mwanza District, equal numbers of participants with different personal attributes (age, gender, marital status) were enrolled. Based on the sample size of previous focused ethnographies (Conte et al., 2015; Kallakorpi et al., 2018), the targeted sample size for this study comprised 20 participants. Data saturation was achieved by the 15th interview; however, five additional interviews were conducted to ensure representativeness of information, increasing the credibility of the findings.

## **Recruitment**

Three qualified nurses employed at the clinic assisted with the purposeful identification and recruitment of participants in the study. The nurses were briefed on the study objectives, inclusion criteria, and procedures before the recruitment process began and were provided with the opportunity to ask questions and clarify any unclear area. These nurses identified potential participants attending the HIV clinic and provided prospective participants with research packets containing consent or assent forms (for participants younger than 18 years ) and study-specific information. Participants younger than 18 were also given consent forms for completion by their responsible caregivers. The study information and consent forms were read to one illiterate participant and her guardian at the clinic, and thumbprints were used as signatures. Only participants who returned signed consent/assent forms to the study's principal investigator (M.Z.) or the clinic's nurses were scheduled for an interview. Twenty-two of the identified 26 potential participants returned the signed consent/assent forms. Of the 22 participants returning signed consent/assent forms, two participants were not interviewed; one had a hearing disorder, which had the potential to impact communication, and the second individual did not come for the scheduled interviews.

## **Ethical and Data Collection Procedures**

Ethical approval was obtained from the Edith Cowan University Human Research Ethics Committee (#20628) and the National Committee on Research in Social Science and Humanities in Malawi (#P.12/18/340). Before interviews, all participants were asked to confirm that they understood the research information, voluntarily provided their informed consent, and agreed to audiorecording the interview. All participants were given pseudonyms before an interview to protect confidentiality. Depending on the time for the interview and distance to the clinic, some participants ( $n = 17$ ) were refunded transport money and given lunch allowances.

Data were collected by M.Z. through in-depth interviews, which included the recording of detailed field notes, between January 26, 2019 and May 17, 2019. A structured interview guide was used to collect data. The first part of the interview guide included questions on demographic information: age, education, religion, employment status, marital status, and living conditions. The second section of the interview guide used open-ended questions related to the mode and process of HIV disclosure, perceptions of HIV disclosure, and any perceived barriers and/or challenges encountered with disclosure (Table 1). The interview guide was developed in English and translated into Chichewa (the local language for Mwanza District) by a team of bilingual professionals to ensure equivalence and cultural and linguistic sensitivity (Douglas & Craig, 2007). The interview guide was then piloted, before use, on two youths living with HIV (data not included herein), leading to refinement of the interview guide. A refined set of probes was used together with the main questions to elicit more information from participants. Depending on an individual's responses, probes varied in use, wording, and order (e.g., "how did you tell them?").



**Table 1. Interview Questions on Disclosure of HIV Status**

1. How did you find out that you are living with HIV? When?
2. What do you think caused your problem? When?
3. Do you manage to discuss your status with other people? <ul style="list-style-type: none"><li>• How about your sex partner?</li><li>• Why did you decide to disclose your status?</li><li>• How did you tell them?</li></ul>
4. How did your partners react to the disclosure?
5. Has disclosing your HIV status affected you in any way? Your health? Medication? Social life?
6. When you think of disclosing HIV status, what helps? What affects you most?
7. What are/were your biggest fears about disclosing your status to your partner?

All interviews took place at the outpatient clinic and were conducted in a private room; M.Z., a native Malawian and fluent in the Chichewa dialect, conducted the interviews. Interviews lasted between 21 and 56 minutes and all were audiorecorded. Half ( $n = 10$ ) of the participants had repeat interviews to clarify and add information; these repeat interviews were selected based on gaps identified in their information during the preliminary data analysis. Field notes recorded by the interviewer included notes on casual observations of participants, the physical environment of the clinic, and a personal reflection written soon after each interview.

## **Data Analysis and Management**

A total of 20 interviews were completed. After each interview, audio recordings were uploaded into a password-protected computer, and the digital recorder was cleared daily. All digital research materials were removed from the computer and uploaded onto the University's password-protected central cloud drive, while hard materials were kept in a locked cabinet accessible only to the researchers. The interviewer transcribed the audio recordings verbatim, and personal identifiers such as names of villages and schools were assigned pseudonyms during transcription for confidentiality. Forward and back translation to English was done by four bilingual translators (Chichewa and English) and bound by confidentiality, as recommended by the World Health Organization (WHO, 2019b).

Using an inductive approach, manual thematic data analysis was undertaken following the guidelines by Braun and Clarke (2006). All authors of this manuscript read and re-read the transcripts to familiarize themselves with the data before beginning the analysis. Data analysis started with each author open coding raw data independently and grouping similar codes into categories. Categories with similar meanings were linked to identify the meaning and pattern of relationships and the classified codes, which were then discussed by all authors to formulate themes. Extracted themes were cross-checked against the data to verify the following: (a) the verbatim quotes used to identify the themes, (b) the codes represented the participants' quotes, and (c) the relationship between the codes, categories, and identified themes was a true reflection of the data. Researchers held regular meetings to discuss and agree on the emerging patterns of themes. Decisions on discrepancies were discussed and followed the majority rule. The authors are all female nurses with research backgrounds. M.Z. is a Malawian undertaking doctoral studies in Australia; D.A. and D.I. are

Australians with postgraduate qualifications and many years of experience in conducting similar research.

## **Rigor**

Alongside the in-depth interviews with the youth living with HIV, other data were also sourced from the written contemporaneous field notes on casual observations, which enhanced the credibility of this study. All interviews were carried out in the local language for the participants, to give comfort and facilitate rapport building. In addition, all data materials were recorded in Chichewa to preserve meaning and cultural context for dependability. The study used the interpretivism paradigm, which is based on the beliefs and perceptions the researcher has about the social environment (Whitehead et al., 2018). However, having a team of three researchers with different cultural backgrounds facilitated neutrality and dependability in the analysis and data interpretations (Cope, 2014). All authors practiced reflexivity by meeting regularly to discuss possible biases during analysis and to agree on the identified themes. M.Z. kept a reflective journal that helped to document notes from observations of behaviors and to reflect on points or feelings about which the researcher wanted to clarify or theorize outside of the interview. This reflective journal was also used for recording a decision trail undertaken at every research stage for dependability. Chichewa transcripts were given to 16 traceable participants for member checking to clarify and confirm data before translation into English.

After data analysis, an external academic researcher in child and adolescent health and research in Malawi, who was not involved in this study, reviewed the data, codes, and the identified themes to confirm accuracy in data analysis. This external review, and our methodology as described above, enhanced the study's credibility (the truth of results), dependability (consistency in findings by another researcher over similar conditions),

confirmability (minimizing researchers' bias in data interpretation to represent participants' views), transferability (applicability of findings to other settings), and authenticity (an expression of the true feelings of the participants in the quotes) for trustworthiness (Cope, 2014).

## **Results**

### **Characteristics of Study Participants**

The study included 10 males and 10 female Malawian participants between the ages of 15 and 24 years (Table 2). Participants in the study had been aware of their HIV status between 6 months and 15 years. Most of them were unmarried ( $n = 14$ ), with the majority having current or past sexual relationships ( $n = 18$ ). Six participants (five females and one male) were married, and all had disclosed their HIV status to their spouses. In contrast, of the nine participants who were sexually active but not married, none had disclosed their HIV status to their past or present sexual partners. Disclosing one's HIV status to a sexual partner or partners, by unmarried participants, was uncommon ( $n = 3$ ; Table 2).

Generally, participants were aware of the source of their HIV infection: 11 participants acquired HIV vertically, eight participants were infected through sexual contact, and one participant was unaware of the source of infection. Only three out of nine participants who had acquired HIV vertically had disclosed their HIV status to their sexual partners. In contrast, six of the eight respondents who had acquired HIV through sexual contact had disclosed their HIV status to sexual partners. Participant characteristics are presented in Table 2.

**Table 2. HIV Status Disclosure and Participants' Sexuality**

Participant's Names*	Sex	Age	Disclosed to Sexual Partner	Marital Status	Mode of Infection	Current Sexual Partner (s)	Partner's HIV Status	Number of Lifetime Past Partners	Ever Had Sex
Lonjezo	F	17	Yes	Unmarried	Vertical	1	Negative	-	Yes
Alefa	F	17	No	Unmarried	Vertical	5	Unknown	-	Yes
Mphatso	F	18	Yes	Unmarried	Sexual	0	Positive	2	Yes
Omega	F	20	Yes	Married	Sexual	1	Positive	2	Yes
Mary	F	21	No	Unmarried	Sexual	0	Unknown	1	Yes
Malita	F	21	No	Divorced	Sexual	1	Unknown	2	Yes
Tamanda	F	22	Yes	Married	Sexual	1	Positive	>2	Yes
Gonjetso	F	22	Yes	Married	Sexual	1	Positive	2	Yes
Yankho	F	23	Yes	Married	Vertical	1	Positive	1	Yes
Maya	F	24	Yes	Married	Sexual	1	Positive	4	Yes
Funsani	M	24	Yes	Married	Sexual	1	Positive	7	Yes
VTsonga	M	23	No	Unmarried	Unknown	0	Unknown	3	Yes
Dalitso	M	20	No	Unmarried	Vertical	1	Negative	0	Yes
Chimwemwe	M	19	No	Unmarried	Vertical	1	Unknown	-	Yes
Kondwani	M	18	No	Unmarried	Vertical	1	Unknown	1	Yes
Mada	M	18	Yes	Unmarried	Vertical	1	Positive	0	Yes
Jonasi	M	18	No	Unmarried	Vertical	0	Unknown	1	Yes
Takondwa	M	17	N/A	Unmarried	Vertical	0	N/A	0	No
Mwayi	M	16	No	Unmarried	Vertical	1	Unknown	-	-
Thoko	M	15	N/A	Unmarried	Vertical	0	N/A	0	No

Note. N/A = not applicable; - = missing data; F = female; M = male.

\*Pseudonyms.

Four themes were identified from the analysis: (a) perspectives about the mode of HIV disclosure to sexual partners, (b) reported consequences of HIV disclosure, (c) perceived barriers to HIV disclosure to sexual partners, and (d) perceived facilitators for HIV disclosure.

## **Perspectives About the Mode of HIV Disclosure to Sexual Partners**

Participants who had disclosed their HIV status to sexual partners reported different ways of disclosing, including (a) planned disclosure, (b) accidental disclosure, (c) routine HIV disclosure by health workers at the HIV clinic, and (d) forced disclosure through a lawsuit. Regarding planned disclosure, participants disclosed their HIV status privately, at home, after receiving the results of their HIV test at the antenatal clinic, as part of routine care during pregnancy. Tamanda, a 22-year-old female, said: “I knew my status when I was pregnant and attending the antenatal clinic, that’s when I got tested for HIV. Then they asked me a lot of questions, and later they gave me the medication. I told my husband.”

In general, the HIV clinic in Mwanza is open to public view. Youth attending the clinic could be easily associated with HIV and thus risk accidental disclosure of their HIV status. In this case, youth attending the clinic could be identified through deliberate observation, accidentally, or by other attendees at the clinic. For example, some participants believed that their sexual partners assumed their HIV status after spotting them at the clinic before their sexual relationship commenced. Disclosure of HIV status for such participants was a confirmation of the assumptions made by their sexual partners. “I found her here [clinic]; she was already infected.” (Funsani, a 24-year-old male) Likewise, another participant added, “She also has the same condition. I didn’t give her the virus; she was already like this before we met. I used to see her here before our relationship started” (Mada, an 18-year-old male).

Female participants described routine or couples’ HIV testing (which was encouraged) by health workers at the hospital as the impetus for disclosure. Their spouses became aware of their HIV status after escorting them to the hospital, where they were further investigated and tested for HIV as a couple or in the presence of the partner. “I was

sick ... he [husband] ... called one of his women friends from the hospital to assist ... then she brought us here, and I got tested” (Gonjetso, a 22-year-old female). Similarly, another female participant stated, “I was found with HIV when I was pregnant with this baby. I came with my husband to the antenatal clinic, and we were tested for HIV. Both of our HIV results came out positive” (Maya, a 24-year-old female).

The following example of HIV disclosure was a requirement for lawsuit proceedings against a husband for marrying an underage female partner. The female participant and her husband were tested:

There was a letter to subpoena us saying “John [pseudonym for husband] and his wife are needed at the police.” The Group Village Headman had sued my mother for marrying off an underage girl (the participant was younger than 18 years old when she married). They [the police] demanded that I get tests for sexually transmitted infections ... and pregnancy. So, I went with John, and we got tested ... two stripes came up, meaning it was positive. (Mphatso, an 18-year-old female)

### **Reported Consequences of HIV Disclosure**

Participants reported subsequent difficulties with their relationships after disclosing their HIV status to their partners. They experienced a relationship breakdown related to disclosure. For instance, one participant disclosed her HIV status to her boyfriend, who was not living with HIV, and he gradually distanced himself and stopped all communication with her. She stated, “He is currently in Mangochi, but he doesn’t call me these days. I have also heard that he intends to marry another woman. As such, I don’t call him either” (Lonjezo, a 17-year-old, pregnant female). Another male participant believed that one of his past girlfriends left him without “proper goodbyes” because he was falling sick often. He stated,

“I was falling sick frequently, so the relationship did not work out; she must have suspected that I have HIV” (Tsonga, a 23-year-old male).

Polygamous relationships are common and legally accepted in Malawi (PLAN International, 2016). It is estimated that 13 out of 100 women in Malawi are in a relationship with a man who has other wives (Malawi National Statistical Office & ICF International, 2017). For Tamanda, who was in a polygamous marriage, her husband left her to live with his first wife for awhile after she disclosed her HIV status. “He got angry and left the house; then he came back and said, ‘Tamanda, I won’t do it again, look at me, I am also taking the medication’” (Tamanda, a 22-year-old female).

Participants who did not disclose their HIV status did not feel it necessary, as they thought their partners were already living with HIV and were aware of their HIV status but concealing it:

I never disclosed this to the father of my child up to date. I just told him that ... since I was very angry, I called him to say it’s over between us ... he doomed my future. If he had disclosed to me, it could have been different, but he wasn’t truthful with me.  
(Participant was visibly angry: Field notes; Mary, a 24-year-old female)

Similarly, another participant said,

It is my husband who infected me ... he kept it from me; he killed me. If he were someone else, he would have asked me to go with him to the hospital for an HIV test or rather tell me that he went for an HIV test and he was found positive; but he chose to keep it a secret first. He waited till I fell sick, that’s when he brought me here for a test. (Gonjetso, a 22-year-old female)



## **Perceived Barriers to HIV Disclosure to Sexual Partners**

Among participants who were sexually active, disclosing HIV status to sexual partners was a significant problem, especially among unmarried participants. The main reasons for concealing their HIV status were concerns about confidentiality and a lack of trust in their sexual partners to keep their HIV status a secret. The concerns about maintaining the confidentiality of the information is illustrated by Jonasi, an 18-year-old male participant who stated, "... it [status disclosure to sex partner] cannot happen because no one can keep my secret. It cannot happen, never."

To protect their privacy, respondents intentionally kept their disclosure circles small because unwanted disclosure meant enlarging the circle of those knowing their HIV status. Participants believed that the more people who came to know their status, the higher the chances were of being gossiped about and/or stereotyped as a prostitute/womanizer: "I just fear that maybe when my friends hear about my HIV status, they will discriminate me. People commonly think you got infected with HIV because you are a slut" (Maya, a 24-year-old female). In turn, it could lead to social isolation or exclusion from the use of communal amenities and work opportunities. Another participant stated, "If I tell my neighbor, I will be stigmatized. The neighbor will stop sharing food with me or offer fewer job opportunities, while concluding that I am a prostitute. It is better that I tell no one" (Mary, a 24-year-old female). The perceived consequences from enlarged disclosure circles were assumed to impede communication of HIV status to sexual partners.

In this study, unmarried participants were more reluctant to disclose their HIV status to sexual partners than married participants. They feared the potential harm that HIV disclosure could have on their relationship. Specifically, participants verbalized fear and anxiety about the relationship breaking down and becoming unstable due to HIV status

disclosure. For example, “No, I didn’t disclose my status [to ex-boyfriend], I was worried he would dump me” (Yankho, a 24-year-old female). Similarly, “I think this [disclosure] can cause misunderstandings in our relationship ... she can’t understand me. To prevent fights or to let her disclose my status to other people, I just stay quiet” (Mwayi, a 16-year-old male).

More likely, a perceived short-term commitment negatively influenced the “insecure feelings” of those in early boyfriend/girlfriend relationships, considering that almost all married participants in this study had disclosed their HIV status to their sexual partners.

### **Perceived Facilitators for HIV Disclosure**

The motivation to disclose HIV status to sexual partners was inherent and emotionally influenced. For example, love and the desire to protect partners were the motivations for participants to disclose to their partners, as narrated by Lonjezo, a 17-year-old female, “because I loved him [boyfriend], I was troubled that I might infect him. I told him my status.” Performing the HIV test together as spouses and meeting their future spouses at the HIV clinic before courtship also increased the spouse’s opportunity to know a participant’s HIV diagnosis.

### **Discussion**

The findings indicate that Malawian youth living with HIV generally struggled to disclose information about their HIV status and frequently delayed disclosure. Failure to disclose one’s HIV status to a sexual partner can have detrimental consequences, including the avoidable transmission of HIV (Yaya et al., 2015). The results portray a picture of a young person caught in a conflict between protecting their private information while living with HIV. The youth living with HIV are torn between two different, but equally compelling,

moral imperatives: first, intentions to maintain love and long-term relationships while, second, protecting oneself from stigmatization and/or rejection by sexual partners.

Generally, unmarried participants were found to struggle with disclosing their HIV status to their sexual partners. This study supports findings from previous studies in which cultural and social setting factors negatively affected the disclosure of HIV status to spouses by more unmarried than married participants (Hampananda & Rael, 2018; Ojikutu et al., 2016). Married participants are more likely to disclose HIV serostatus to their partners because of the perceived proximity to their spouse, frequent clinic visits, and daily medication influence (Knettel et al., 2019). We also suggest that being married provides ease of communication and some assurance for a long-term relationship. Other researchers have previously corroborated the likelihood of disclosing HIV status to partners if the people living with HIV perceive they are part of a committed relationship (Hino et al., 2018).

In this study, participants who acquired HIV through vertical transmission had also lived longer with the diagnosis than those who were infected during adolescence and young adulthood. Research highlights that children growing up with HIV are consistently encouraged by their caregivers not to disclose their HIV status (Kalembo et al., 2018). The effect of growing up while being restricted from disclosing HIV status may have a deep and lasting grip on their comfort and ability to disclose HIV to sexual partners.

Our findings show the disclosure process of HIV status to sexual partners varied between married and unmarried participants. Married participants discovered their HIV diagnosis frequently in the presence of their spouses, who accompanied them to the hospital when they had fallen ill or experienced pregnancy. Participants did not have the opportunity to decide whether (or when) to disclose HIV status to the partner if HIV testing was conducted as a couple. Health programs on disclosure of HIV status to partners in Malawi have intensified the male partner involvement in maternity health care, including spousal

notifications for pregnant women who are found to be living with HIV and having HIV testing carried out at antenatal clinic for couples (Hino et al., 2018; WHO, 2012). Regarding spousal notification, partners of the newly HIV diagnosed individual are sent HIV testing invitation cards (Hino et al., 2018). We suggest these programs may have enhanced the likelihood of partner awareness regarding the HIV status of the married participants in this study. Programs such as universal partner notification should extend to all youth living with HIV as a vehicle for reaching out to their partners for voluntary counseling and testing. This partner notification would enhance HIV status awareness, especially in partners who are reluctant to inform their loved ones of their positive HIV status. This would increase the chances of provider-initiated HIV status disclosure if the HIV test is conducted as a couple.

Unmarried participants in this study frequently reported failure to entrust their sexual partners with their HIV diagnosis. They believed that “no one can keep their secret” and, therefore, disclosure of HIV status to sexual partners “cannot happen, never.” Since the onset of the HIV pandemic, fighting HIV-related stigma and discrimination has been an important aspect of HIV programs; however, people living with HIV continue to experience related challenges to stigma and discrimination. This suggests that health care workers need to be involved with community-driven health initiatives and advocate for the improvement of youths’ health overall. For many years, interventions to fight HIV-related stigma and discrimination have targeted the community through health education and awareness (Stangl et al., 2013). In this study, fear of the reaction of the community was found to be the core and genesis of other factors related to fear of HIV status disclosure. We argue that HIV programs designed to reduce stigma and discrimination should commence education with the involved individuals living with HIV, then move outwards to incorporate the community. Youth living with HIV should be empowered with social skills to boost their self-esteem, develop resilience, and be given a voice to speak for themselves as a unique group living with HIV.

National policies designed to protect youth living with HIV in terms of disclosure of HIV status and equal opportunities should be reinforced, while youth should be taught and encouraged to know their rights to access equitable health care and social standing.

One of the most frequently given reasons for their HIV status concealment from sexual partners was fear that their sexual partners would accidentally reveal their diagnosis to the community, thereby simultaneously exposing them to stigmatization, discrimination, and prejudice. Participants in this study described both actual and perceived stigma and discrimination. Other researchers have found that people living with HIV are denied equal opportunities because of the misconception that casual contact has the potential to transmit HIV (Wong & Nur Syuhada, 2011). In addition, living with HIV is translated into being promiscuous/womanizer, which is a culturally unacceptable behavior that deserves “punishment” in some religious communities and results in community isolation (Adia et al., 2018; Watts & O’Byrne, 2019; Wong & Nur Syuhada, 2011). This study relied on data from youth living with HIV only, and it is essential to examine the perceptions of other people in the community on how to best support this population. It will be important to empower the youth population with skills and a voice, as well as to target all society members with HIV educational programs on stigma and discrimination.

For some participants, the fear of disclosing their HIV status to their sexual partners was overcome by love and a desire to protect their partners. Although the uncertainty of love and relationships is inevitable, youth living with HIV might benefit from coaching on life skills and decision making to promote resilience and self-esteem. Transparent decisions in sexual relationships may improve youth well-being and facilitate communication. Disclosure of HIV status to partners to prevent transmission of HIV and access to relevant or appropriate support services are vital in the uptake of HIV health services (Chapman et al., 2020).

Therefore, disclosure of HIV status to sexual partners is of paramount importance among this

population, considering that findings from a large multisite clinical trial in Botswana indicated that youth living with HIV lag on the uptake of HIV services compared to adults (Wirth et al., 2020). Disclosing HIV status to partners can enhance youth access to social support and provide help in making safer sex choices. It is, therefore, important for a health worker to understand the interplay occurring between the disclosure of HIV status to a sexual partner, love and relationship dynamics, and perceived risk of HIV stigma or discrimination in the broader community.

### **Limitations**

Interpretation of the findings of this study should be made with a comprehension of the limitations of qualitative study designs. This study was conducted at the HIV clinic, which may have influenced participants' responses in terms of comfort and being aware of what behavior is professionally regarded as "acceptable." Although attempts were made to diversify the sample, there was an overrepresentation of married female participants compared to married male participants. This occurred because most females within this age group and presenting at the clinic were already married. Attempts to recruit an equal number of participants from both genders, who were either married or not, slowed down the recruitment process. Delayed recruitment would have affected the study timeline. In addition, these findings are not a reflection of the perceptions of youth living with HIV who may not yet have started HIV treatment programs or those who missed the opportunity to participate in the study because they skipped their clinic appointments during our data collection period. Thus, these limitations may hinder study transferability to other youth populations. Finally, selection bias may have occurred because of personal preferences of the recruiting nurses who had an ongoing nurse-patient relationship with participants.

## **Conclusion**

This study provides insight into critical aspects of HIV serostatus disclosure among youth living with HIV in Malawi and similar settings. Being married in this study provided a long-term sense of belonging and ownership and hence, an ease in disclosing HIV status, unlike unmarried participants, who frequently reported failure to trust their sexual partners with their HIV diagnosis for fear of abandonment and unwanted HIV disclosure. Disclosure of HIV status is highly influenced by the community in which the youth resides. As such, it is suggested that HIV programs designed to facilitate disclosure of HIV status should not only educate people more widely in the community but also equip youth with knowledge and skills to overcome their fear and promote confidence to denounce HIV-related stigma, discrimination, and prejudice.

## **Key Considerations**

- HIV should be treated like other sexually transmitted infections. Each new incident should flag the need to trace, contact, and invite the sexual partner(s) for HIV counseling and testing, and this should apply to both married and single youth.
- Combating stigma and discrimination as a means of enhancing HIV disclosure should involve youth living with HIV, by equipping them with knowledge and life skills to overcome the fear of disclosure and resilience to fight stigma and discrimination at individual and group levels.
- Awareness of HIV and the importance of communicating HIV status disclosure should continue among the youth and members of their communities.

- Equity and rights of youth living with HIV should be upheld in communities, and national policies that protect youth with HIV from community stigma and discrimination should be reinforced.



## References

- Adia, A. C., Bermudez, A. N. C., Callahan, M. W., Hernandez, L. I., Imperial, R. H., & Operario, D. (2018). "An evil lurking behind you": Drivers, experiences, and consequences of HIV-related stigma among men who have sex with men with HIV in Manila, Philippines. *AIDS Education and Prevention*, 30(4), 322-334. <https://doi.org/10.1521/aeap.2018.30.4.322>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>
- Chapman, L. C., Tarver, W. L., Musoke, P. L., Stringer, K. L., Whitfield, S., Turan, B., Modi, R., Mugavero, M. J., Fredericksen, R. J., Weiser, S., Johnson, M. O., & Turan, J. M. (2020,). Complexities of HIV disclosure in patients newly entering HIV care: A qualitative analysis. *Journal of the Association of Nurses in AIDS Care*, 31(2), 208-218. <https://doi.org/10.1097/JNC.000000000000127>
- Colombini, M., James, C., Ndwiga, C., Team, I., & Mayhew, S. H. (2016). The risks of partner violence following HIV status disclosure, and health service responses: Narratives of women attending reproductive health services in Kenya. *Journal of the International AIDS Society*, 19(1), 20766. <https://doi.org/10.7448/IAS.19.1.20766>
- Conte, H., Scheja, M., Hjelmqvist, H., & Jirwe, M. (2015). Exploring teams of learners becoming "WE" in the intensive care unit—a focused ethnographic study. *BioMed Central Medical Education*, 15(1), 131. <https://10.1186/s12909-015-0414-2>
- Cope, D. G. (2014). Methods and meanings: Credibility and trustworthiness of qualitative research. *Oncology Nursing Forum*, 41(1), 89–91. <https://doi:10.1188/14.ONF.89-91>
- Cruz, E. V., & Higginbottom, G. (2013). The use of focused ethnography in nursing research. *Nurse Researcher*, 20(4), 36-43. <https://doi.org/10.7748/nr2013.03.20.4.36.e305>

- Davies, M.-A., Gibb, D., & Turkova, A. (2016). Survival of HIV-1 vertically infected children. *Current Opinion in HIV and AIDS*, 11(5), 455-464.  
<https://doi.org/10.1097/COH.0000000000000303>
- Douglas, S. P., & Craig, C. S. (2007). Collaborative and iterative translation: An alternative approach to back translation. *Journal of International Marketing*, 15(1), 30-43.  
<https://doi.org/10.1509/jimk.15.1.030>
- Elkington, K. S., Bauermeister, J. A., Santamaria, E. K., Dolezal, C., & Mellins, C. A. (2014). Substance use and the development of sexual risk behaviors in youth perinatally exposed to HIV. *Journal of Pediatric Psychology*, 40(4), 442-454.  
<https://doi.org/10.1093/jpepsy/jsu103>
- Evangelini, M., & Wroe, A. L. (2017). HIV disclosure anxiety: A systematic review and theoretical synthesis. *AIDS and Behavior*, 21(1), 1-11.  
<https://doi.org/10.1007/s10461-016-1453-3>
- Hampanda, K. M., & Rael, C. T. (2018). HIV status disclosure among postpartum women in Zambia with varied intimate partner violence experiences. *AIDS and Behavior*, 22(5), 1652-1661. <https://doi.org/10.1007/s10461-017-1909-0>
- Hino, S., Grodensky, C., Rutstein, S. E., Golin, C., Smith, M. K., Christmas, L., Miller, W., Phiri, S., Massa, C., & Kamanga, G. (2018). HIV status disclosure during acute HIV infection in Malawi. *PloS one*, 13(7), e0201265.  
<https://doi.org/10.1371/journal.pone.0201265>
- Kalembo, F. W., Kendall, G. E., Ali, M., Chimwaza, A. F., & Tallon, M. M. (2018). Primary caregivers, healthcare workers, teachers and community leaders' perceptions and experiences of their involvement, practice and challenges of disclosure of HIV status to children living with HIV in Malawi: A qualitative study. *BMC Public Health*, 18, 884. <https://doi.org/10.1186/s12889-018-5820-z>

- Kallakorpi, S., Haatainen, K., & Kankkunen, P. (2018). Psychiatric nursing care experiences of immigrant patients: A focused ethnographic study. *International Journal of Mental Health Nursing*, 28(1), 117–127. <https://doi.org/10.1111/inm.12500>
- Knettel, B. A., Minja, L., Chumba, L. N., Oshosen, M., Cichowitz, C., Mmbaga, B. T., & Watt, M. H. (2019). Serostatus disclosure among a cohort of HIV-infected pregnant women enrolled in HIV care in Moshi, Tanzania: A mixed-methods study. *SSM - population health*, 7, 100323. <https://doi.org/10.1016/j.ssmph.2018.11.007>
- Malawi National AIDS Commission. (2015). *Malawi AIDS response progress report*. [https://www.unaids.org/sites/default/files/country/documents/MWI\\_narrative\\_report\\_2015.pdf](https://www.unaids.org/sites/default/files/country/documents/MWI_narrative_report_2015.pdf)
- Malawi National Statistical Office & ICF International. (2017). *Malawi: 2015-2016 Demographic Health Survey Key Indicators*. <https://dhsprogram.com/pubs/pdf/FR319/FR319.pdf>
- Mandalazi, P., Bandawe, C., & Umar, E. (2014). HIV disclosure: Parental dilemma in informing HIV infected children about their HIV status in Malawi. *Malawi Medical Journal*, 26(4), 101-104.
- Mengwai, K., Madiba, S., & Modjadji, P. (2020). Low disclosure rates to sexual partners and unsafe sexual practices of youth recently diagnosed with hiv; implications for hiv prevention interventions in south africa. *Healthcare*, 8(3), 253. <https://doi.org/10.3390/healthcare8030253>
- Nhamo-Murire, M., Campbell, C., & Gregson, S. (2014). Community group membership and stigmatizing attitudes towards people living with HIV in eastern Zimbabwe. *Journal of Community Health*, 39(1), 72-82. <https://doi.org/10.1007/s10900-013-9741-6>

O'Connell, A. A., Reed, S. J., & Serovich, J. A. (2015). The efficacy of serostatus disclosure for HIV transmission risk reduction. *AIDS and Behavior*, *19*(2), 283-290.

<https://doi.org/10.1007/s10461-014-0848-2>

Ojikutu, B. O., Pathak, S., Srithanaviboonchai, K., Limbada, M., Friedman, R., Li, S., Mimiaga, M. J., Mayer, K. H., Safren, S. A., & Network, H. P. T. (2016). Community cultural norms, stigma and disclosure to sexual partners among women living with HIV in Thailand, Brazil and Zambia (HPTN 063). *PloS One*, *11*(5), e0153600.

<https://doi.org/10.1371/journal.pone.0153600>

Pindani, M., Nkondo, M., Maluwa, A., & Muheriwa, S. (2014). Stigma and discrimination against people living with HIV and AIDS in Malawi. *World Journal of AIDS*, *4*(02), 123-132. <https://doi.org/10.4236/wja.2014.42016>

PLAN International. (2016). *In-depth review of legal and regulatory frameworks on child marriage in Malawi*. [https://www.fillespasepouses.org/wp-content/uploads/2016/11/PLAN\\_18\\_country\\_report\\_malawi\\_final.pdf](https://www.fillespasepouses.org/wp-content/uploads/2016/11/PLAN_18_country_report_malawi_final.pdf)

Stangl, A. L., Lloyd, J. K., Brady, L. M., Holland, C. E., & Baral, S. (2013). A systematic review of interventions to reduce HIV-related stigma and discrimination from 2002 to 2013: How far have we come? *Journal of the International AIDS Society*, *16*(3), 18734-18734. <https://doi.org/10.7448/IAS.16.3.18734>

UNAIDS. (2018). *Malawi 2016: HIV and AIDS Estimates*.

<http://www.unaids.org/en/regionscountries/countries/malawi/>

UNAIDS. (2019). *AIDSinfo: People living with HIV receiving ART*.

<https://aidsinfo.unaids.org/>

Wall, S.S. (2015). Focused Ethnography: A Methodological Adaptation for Social Research in Emerging Contexts. *Forum: Qualitative Social Research*, *16*(1), 1-15.

<http://dx.doi.org/10.17169/fqs-16.1.2182>

- Watts, J., & O'Byrne, P. (2019). 'I don't care if you think I'm gay ... that won't make me either promiscuous or HIV positive': HIV, stigma, and the paradox of the gay men's sexual health clinic-An exploratory study. *Applied Nursing Research*, 47, 1-3.  
<https://doi.org/10.1016/j.apnr.2019.02.004>
- Weintraub, A., Mellins, C. A., Warne, P., Dolezal, C., Elkington, K., Bucek, A., Leu, C.-S., Bamji, M., Wiznia, A., & Abrams, E. J. (2017). Patterns and correlates of serostatus disclosure to sexual partners by perinatally-infected adolescents and young adults. *AIDS and Behavior*, 21(1), 129-140. <https://doi.org/10.1007/s10461-016-1337-6>
- Whitehead, D., Dilworth, S., & Higgins, I. (2018). Common qualitative methods. In Schneider, Z., Whitehead, D., LoBindo-Wood, G., & Haber, J. (2018). *Nursing and midwifery research: Methods and appraisal for evidence-based practise* (5th ed., pp. 93-109). Elsevier.
- World Health Organization. (2012). *Guidance on couples HIV testing and counselling including antiretroviral therapy for treatment and prevention in serodiscordant couples: recommendations for a public health approach*.  
<https://apps.who.int/iris/handle/10665/44646>
- World Health Organization. (2019a). *Maternal, newborn, child and adolescent health*.  
[https://www.who.int/maternal\\_child\\_adolescent/topics/adolescence/hiv/en/](https://www.who.int/maternal_child_adolescent/topics/adolescence/hiv/en/)
- World Health Organization. (2019b). *Process of translation and adaptation of instruments*.  
[https://www.who.int/substance\\_abuse/research\\_tools/translation/en/](https://www.who.int/substance_abuse/research_tools/translation/en/)
- Wirth, K. E., Gaolathe, T., Holme, M. P., Mmalane, M., Kadima, E., Chakalisa, U., Manyake, K., Mbikiwa, A. M., Simon, S. V., & Letlhogile, R. (2020). Population uptake of HIV testing, treatment, viral suppression, and male circumcision following a community-based intervention in Botswana (Ya Tsie/BCPP): A cluster-randomized

trial. *The Lancet HIV*, 7(6), e422-e433. [https://doi.org/10.1016/S2352-3018\(20\)30103-X](https://doi.org/10.1016/S2352-3018(20)30103-X)

Wong, L., & Nur Syuhada, A. (2011). Stigmatization and discrimination towards people living with or affected by HIV/AIDS by the general public in Malaysia. *Southeast Asian Journal of Tropical Medicine and Public Health*, 42(5), 1119-1129.

Yaya, I., Saka, B., Landoh, D. E., Patassi, A. A., Aboubakari, A.S., Makawa, M.S., N'Dri, M. K., Senanou, S., Lamboni, B., & Idrissou, D. (2015). HIV status disclosure to sexual partners, among people living with HIV and AIDS on antiretroviral therapy at Sokodé regional hospital, Togo. *PloS one*, 10(2), e0118157.

<https://doi.org/10.1371/journal.pone.0118157>